



NEWSLETTER

AIDS NETWORK OF EDMONTON SOCIETY

JANUARY/FEBRUARY 1990

VOLUME 5

NO:1



A NATIONAL AIDS STRATEGY FOR CANADA?



Perrin Beatty, the Minister for Health and Welfare Canada, has spoken about developing a National Strategy on HIV Infection and AIDS to be in place early in 1990.

The Canadian AIDS Society, and other interested groups -- including the AIDS Network of Edmonton Society -- were asked to submit their ideas on that strategy to Sadinsky and Associates. The CAS document; "Working Together: Towards a National AIDS Strategy in Canada" Sept. 1989, led to the development of "A Working Document For the Development of a National Strategy on HIV Infection and AIDS" by Sadinsky and Associates, Oct. 1989. The working document was then submitted to Health and Welfare Canada.

The CAS document contained 77 recommendations under 10 headings: Education and Prevention; Treatment; Care and Support; Testing; Legal and Discrimination Issues; Research; Roles and Responsibilities; Economic considerations regarding AIDS/HIV; International issues; and Managing the national AIDS strategy.

Most of the recommendations were included in the Working Document under 5 objectives. The CAS and interested groups then had the opportunity to respond to the Working Document, which we did in December. Our response included changes and additions to activities so the National Strategy would more completely reflect the CAS document, and/or address other concerns that we as community-based groups felt were important.

The first objective in the working document is to: "Establish the Dimensions and Characteristics of HIV Infection and AIDS in Canada." The activities for this objective included seroprevalence studies, seroepidemiologic studies, surveillance and reporting, reference services, an economic analysis, and human rights issues.

Along with the activities proposed, we recommended that the provinces be encouraged to implement an anonymous reporting system. We also expressed our concern that the cost of the studies being recommended should not take

away from funding for Education/Prevention and Care/Support programs.

The Second objective is to: "Break the Chain of Transmission of Infection -- through cooperative targeted behaviour change programs." The activities are to: look at prevention and education strategies; conduct attitudinal and behavioural research; look at programs to target specific groups; implement a national awareness program; review testing; implement workplace programs and show leadership.

-continued...

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There were two major problems with some activities being recommended - Homosexual/Bisexual men, IV drug users and Street People appear to be given very low priority on targeting programs and the national awareness campaign was too vague. With these two concerns being met, this becomes a strong and important objective.

The third strategic objective is to: "Contribute to the Effort to Develop a Vaccine for HIV Infection and Therapies for AIDS-related disease." Activities looked at a national reference service; research funding; scientific resources; coordination of granting programs; a national clearing house; and joint international research programs.

While we agreed with the activities being suggested, we recommended that Canada should consider taking a leading role in psycho/social research projects since so much is already being done internationally in the biomedical field.

The fourth objective is to: "Ensure That Those Who are Infected, Their Supporters and Care Givers Have Access to Appropriate Treatment, Care and Support Services." The activities proposed are: drug treatment and clinical trials; national psycho/social research; access to services; ways to increase professional care and support; and ways to support community-based and PWA organizations.

We recommended several

changes and additions to the activities to fully meet the objective. The activity around clinical trials and drug costs was too vague. Our recommendations clarified these activities to cover subsidies for drugs and added an "open arm" component to the clinical trial protocol.

The final objective is to: "Strengthen National Mechanism and Partnerships to Facilitate National Collaboration and Cooperation, and to Maximize the use of Available Resources and the Benefits of Collaboration and Cooperation." The working paper proposes the establishing a Canada Council on AIDS - a large body representing all interested groups working directly with AIDS, and smaller sub committees to handle the various issues around AIDS.

We recommended that in addition to this activity, the Minister of Health and Welfare convene an annual conference with his provincial counterparts to discuss the issues around AIDS.

Copies of the CAS document, the Working Paper and the ANE response are available to be read at the Network Office.

- Wayne Hellard

IN MEMORIAM

We wish to reflect with love and respect on the death of Alan B. December 1989, Bob F. December 1989, and Lorne L. March 1990.

We also recall Luis E. 1986, Art. D. 1987, Randy F. 1987, Laurence L. 1987, Gerry J. 1988, Tim M. 1988, Patrick M. 1989, Norval C. 1989, Andrew S. 1989, Margaret F. 1989, George M. 1989, Jamie M. 1989, Sam E. 1989, Paul B. 1989, Terry P. 1989.

EDMONTON MARKS WORLD AIDS DAY

World AIDS Day was commemorated in Edmonton December 1st. with the city's first Candlelight Walk. Approximately 75 people gathered at the University of Alberta Hospital to take part in what was a moving recognition of the impact of AIDS on our collective experience.

The glow of 75 candles illuminated the cold night air, as participants made their way along the route, some solemnly, some exuberant - a fitting testimony to the variety of emotions and experiences this health crisis has precipitated.

Led by Wayne Hellard, a Person-Living-With-HIV, the procession made its way to St. Stephen's College on the University campus. Gathered outside the College, the crowd heard from Marion Dempster, the Chairperson of the Board of Directors of the AIDS Network who urged both that we not forget those among us affected by AIDS, as well as extending our awareness to those affected in other parts of the world.

Wayne affirmed to the crowd his personal feelings hope, as it related both to his own struggle with the disease, and to all

others affected, using the symbol of the candle as a metaphor. The crowd quietly sang along to "That's What Friends Are For" - a meaningful expression of the universal, unconditional love that has come out of this crisis for so many.

Barry Breau, Executive Director of the Network, brought greetings from Rev. William Roberts, MLA for Edmonton Centre, and the entire New Democrat Official Opposition Caucus, unable to attend as they were gathered in Winnipeg for the national convention.

"The theme, 'Our Lives, Our World, Let's Take Care of Each Other' is a challenge to each of us whom you have chosen to serve as your elected representatives. Know that we walk with you tonight in spirit" wrote Roberts.

A short reception was held afterwards in St. Stephen's College. The World AIDS Day Candlelight Walk was a success in many ways, especially in affirming the triumph of the human spirit that transcends the sadness and the pain.

-Shawn R. Mooney

Dear Editor,

As I sit at my table, this frosty Sunday morning, sipping my first cup of coffee I'm reflecting on my life. Sundays do that to me!

My thoughts are of my friend, whose mind has gone... for which I have already mourned...but whose body still exists. Even as I sit here I can hardly believe the rapidness of it all. This reality truly is transitory.

My friend was a gently man, though strong in stature. He had the innate ability to communicate in such a calm rational human way. We met at Respiratory Services as the U of A Hospital Oct. '89. It was due to him that I was able to start to deal with all those fears, the isolation, the diagnosis of AIDS. In those beginning weeks and months he calmed my abstract fears, helping me, counselling me, reminding me that with the great sadness we share is included, perhaps as a buffer from God, very very great joys.

I love you buddy and I miss you...you will always be with me...and when I make my transition to join you it will be very, very joyful.

-Dana King
PLWHIV March 11/90

CANADA STREET YOUTH AND AIDS

According to a report, recently released by Queen's University, more than 100,000 young Canadians have left home or school and are not being reached by conventional AIDS education and prevention program. It has been estimated that as many as 500 of those street youth are HIV positive.

The Queen's study is the first comprehensive profile of street youth in Canada. Based on interviews with more than 700 street youth in 10 cities across the country, the study features commentary from the young people about themselves. Questions included information about their families, drug habits, sexual practices, hopes, aspirations, schooling and knowledge about AIDS.

According to the study, almost two thirds of street youth have had five more sexual partners and one-third never use condoms. More than half of the youth surveyed said they were worried about contracting AIDS.

Because of their lifestyles these young people are at a much higher risk of contracting and transmitting the HIV virus than their school going counterparts. Due to their street lifestyle these youth are difficult to reach with up-to-date AIDS information. At the greatest risk of contracting AIDS among

street youth are male prostitutes. Nine out of ten reported having had one or more same sex partners, more than half of those had engaged in anal sex. Despite the risk many said they did not use condoms with their friends or lovers and could be persuaded to forego the use of a condom, with a client, if offered more money.

The Queen's study makes several suggestions to reach street youth. It advocates a national campaign to provide a full range of health and social programs. The campaign would include; a national AIDS education program, a campaign to provide condoms to the youth (at little or no cost), a national clean needle campaign and a nation-wide HIV testing program for street youth that guarantees easy access, counselling and confidentiality.

It is suggested that people supplying education and social programs work to make the threat of AIDS clear to street youth. The message should be kept clear, simple and forceful. The report also suggests that Federal agencies use information about how street youth live to plan strategies that will reach as many of these young people as possible.

*Carlyle Cupid



VOLUNTEER APPRECIATION WEEK

To thank our volunteers a series of inservices will be held on April 28-29, at the ANE office.

AIDS/HIV Update (AIDS 20-2), April 28, 9:00 am - 12:00 noon. This session will cover new drugs and their availability, legal issues and the Public Health Act.

Alternate Therapies, Saturday April 28, 1:00 pm - 4:00 pm.

Art Therapy, Corry Roach
Music Therapy, Marjorie LaPlante
Massage Therapy, TBA
Bioenergetics, TBA

Grieving our everyday losses, Sunday, April 29, 1:00 - 4:00 pm.

VOLUNTEER SOCIAL TO BE HELD ON THURSDAY, APRIL 26, 7:00 - 9:30 PM, AT THE ANE OFFICES.



AIDS AND SURVIVAL ... GOOD NEWS

A research team at the University of California, San Francisco, has released an important study - Long-term AIDS Sufferers. The team of George F. Solomon, M.D., Lydia Termoshok, Ph.D., and Jane Zich, Ph.D., discovered 16 common factors significant to Long Term Survival after an AIDS diagnosis. The researchers tried to understand how long-term survivors are different from people who follow the expected course of the disease.

"While the prevalent belief... is that AIDS is invariably fatal, there is a growing number of individuals who are alive and well three, four, and even five years after an AIDS diagnosis". Citing California Department of Health Services analysts, they state that 50% of AIDS patients will survive a year, 30% two years, and 20% survive five years. If there are currently 41,000 diagnosed cases, then 820 of those people will still be alive in five years. A number of common factors thought to be significant to long-term survival were described:

1) Long term survivors understand and accept the reality of the AIDS diagnosis, but also refuse to believe that the syndrome is an automatic, imminent death sentence.

2) They believe that one can cope actively with the disease, and re-

fuse to succumb to a "helpless-hopeless" state.

3) They make appropriate, individualized adjustments in personal habits and behaviours to accommodate living with the disease.

4) They see the physician as a collaborator, and do not fall into a passive or compliant mode when interacting with the physician; they take an active part in decisions related to treatment.

5) They display a belief that the individual patient can influence the outcome of the disease: a sense of personal responsibility for health.

6) There is a perceived "commitment to life" to take care of unfinished business; a sense of unfulfilled goals or dreams.

7) Survivors find meaning and purpose in life.

8) They identify a sense of meaning in the disease itself.

9) There is usually a previous experience with beating a life threatening illness, or overcoming difficult situations and events.

10) A program of exercise and physical fitness is a common factor.

11) Long-term survivors report the importance of support and information from other people with AIDS, particularly shortly after diagnosis: no one understands quite like another person with AIDS.

12) Commitment to helping other persons with AIDS seems to have a sustaining quality in and of itself.

13) Long-term survivors seem to share a basic level assertiveness and the ability to say "no".

14) Long term survivors give themselves permission to withdraw from involvements when they need to care for themselves.

15) There is a developed ability to "read" one's body, and to sensitively care for it.

16) There seems to be a common ability to communicate openly, including concerns about health issues.

Interestingly, the authors suggest that gay men who have to be comfortable and open about being gay tend to adopt more smoothly to living with their diagnosis of AIDS than those for whom coming out is still an issue. The authors stress that this is a preliminary report, and should be "interpreted with caution". As the study continues, it is hoped that more will be learned about why some people live longer with AIDS. That will eventually enable more people to live longer than the usual prognosis.

(Reprint from Saskatchewan PLWA Network Newsletter)

AIDS NETWORK/U OF A RESEARCH FUND

The AIDS Network/U of A Research Trust Fund, established January of 1988 for the support of basic and applied research into Acquired Immuno Deficiency Syndrome (AIDS), is poised to begin its work. With \$13,7000 in its account, administrators are looking at making their first endowments to local research, in the spring of 1990.

The Trust Fund was set up to get money where it is needed as quickly as possible. To achieve this, 50% of monies donated goes to building the endowment fund while the remaining 50% goes directly into small grants. This method avoids the necessity of waiting a number of years until there is enough money to make endowments from the interest.

The Trust Fund is held by the University and may receive donations from any source. All money donated to the fund is eligible for matching provincial grants. Rimbeay Junior/Senior High School has held two annual fundraising events, in 1988 they raised \$700 and in 1989 their total was \$900. Donations have also been received from the Roost who held their 5th annual fundraiser on November 11, 1989.

can contribute to AIDS Research and be assured that the money will be used in Alberta. Donations can be made through the AIDS Network of Edmonton Society, 10704 - 108 Street, Edmonton, T5H 3A3 or the AIDS Network/U of A Research Fund--c/o Development office, 450 Athabasca Hall, University of Alberta, T6G 2E8. Donors will receive a tax-deductible receipt.

*Carlyle Cupid



ROSS ARMSTRONG
MEMORIAL
TRUST FUND

Opening	
Balance	6405.83
Donations	1197.89
Memberships	1955.00
Interest	203.72
	<hr/>
	9762.44
less grants	7708.00
Balance as of	
Feb. 28/90	2054.44

AN UPDATE ABOUT
INTERNATIONAL TRAVEL

The Sixth International Conference on AIDS greatly benefits from participation by people with HIV/AIDS. United States travel policy prior to May 25, 1989 completely prohibited entry by HIV-infected people. U.S. regulations now permit HIV-infected people to visit the country for up to 30 days to attend conferences, visit relatives, conduct business, seek medical treatment. The amended policy came about through the involvement of the Conference organizers and many other interested groups. Currently, HIV-infected individuals are required to apply for a waiver from the U.S. embassy in their own country 60 days before travelling to the U.S.

The organizers of the Sixth International Conference on AIDS oppose all restrictions on travel for HIV-infected people and will continue to work toward eliminating such restrictions and ensuring confidentiality for HIV-infected travelers.

In future mailings, we will keep you informed about any new developments in this area.



There are two ways people

Upcoming Events

1) VOLUNTEER APPRECIATION WEEK - APRIL 22-28, 1990

To thank our wonderful volunteers for all their time and dedication a Volunteer Appreciation Social will be held on Thursday April 26, 7-9 p.m. in the Network Boardroom.

2) VITALIZE '90 "VOLUNTEERISM - THE CHALLENGE OF THE DECADE"

A Provincial conference hosted by the Wild Rose Foundation June 7,8 and 9 in Red Deer, Alberta. Contact Winston McConnel at 422-9305 or write to Suite 2100, Royal LePage Bldg., 10130-103 Street, Edmonton, T5J 3N9.

3) HIV/AIDS AND YOUTH NATIONAL CONFERENCE.

University of Toronto, May 13-15, 1990. Looks at a proactive approach to HIV/AIDS education and prevention among Canada's youth. For information phone Joanna Vettese (416) 979-5164 or FAX (416) 979-5341 or write Conference on HIV/AIDS and Youth, Ryerson Polytechnical Institute, 350 Victoria Street, Toronto, Ont. M5B 2K3.

4) AIDS EDUCATORS CONFERENCE CALGARY CONVENTION CENTRE OCT. 29 & 30, 1990

Will look at building skills of attendees and focus on educational strategies and evaluation tools to test the effectiveness of

different educational interventions. For information phone AIDS Calgary Awareness Association (403) 228-0155.

5) STAIRCASE CHALLENGE - APRIL 12, 1990

Grant McEwan College, Alumni Association is sponsoring their 1990 staircase challenge at Seventh Street Plaza campus on April 12 as a benefit for the AIDS Network. For information and pledge cards phone 424-4767.

BOOK REVIEW

Matters of Life and Death, Women Speak About AIDS

Ines Rieder and Patricia Ruppelt (ed.)

Virago Press, London 1989

I was delighted to finally find a book about AIDS from a woman's perspective. As a woman who has been affected by AIDS, with the death of a life long friend, it was encouraging to know I was not alone.

Matters of Life and Death is divided into seven sections containing the experiences of several women. The areas covered include: Family, Lovers and Friends; Women with AIDS/ARC and HIV Positive Women; The Professional Caregivers; Lesbians

Facing AIDS; Prostitution in the Age of AIDS; Becoming Visible: Women AIDS Educators and AIDS Prevention Policies. This book gives a good insight into how women see themselves within the AIDS issue as caregivers, loved ones, and persons infected themselves. The women interviewed in this book speak openly and honestly about their fears, concerns, anger and hope.

Many women do not consider themselves at risk or that the issue of AIDS won't touch them. This book clearly shows that this is a gross misconception. AIDS touches everyone. As one woman put it, "We must not stand by while stigmatized groups - female and male - are blamed. Because, in the end, it doesn't only damage specific groups, but all of us."

I would highly recommend this book to anyone interested in the psycho/social issues around AIDS or anyone who themselves have been affected in some way by this disease. It is especially valuable in that it allows us to look at the issue of HIV infection/AIDS from a women's perspective. At a time when there is a lack of good material for women and about women, this book has allowed women to speak out.

- Heather Viveiros

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10704 - 108 Street
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T5H 3A3

**Telephone Number:**

Info Line: 429-AIDS (2437)
Business Line: 424-4767

Office Hours:

Monday - Wednesday 9 am - 6 pm
Thursday 9 am - 9 pm
Friday 9 am - 6 pm

Information Line Hours:

Monday - Thurs 9 am - 9 pm
Friday 9 am - 6 pm
Saturday 11 am - 3 pm

The newsletter is published monthly by the AIDS network of Edmonton Society with the financial assistance from the HEALTH PROMOTION DIRECTORATE OF HEALTH AND WELFARE CANADA AND LEVI STRAUSS CO. (Canada) Inc.

The AIDS Network of Edmonton Society, incorporated in February, 1986, is a non-profit charitable organization (Reg. #0747212-11-25).

MEDICAL RESEARCH

Donations to AIDS Research can be made through the AIDS Network Research Trust Fund, administered by the University of Alberta. Donations are matched by provincial funds, and a charitable receipt is available.

The mandate of the AIDS Network is to provide support to those affected by AIDS and to educate and inform with a view to limiting its spread.

INFORMATION

An informational and support telephone line operates Monday - Saturday. Pamphlets and a lending resource library are available to agencies and the public.

EDUCATIONAL

A speakers bureau provides speakers for educational presentations to concerned groups.

Audiovisual materials and information files are available on loan.

COUNSELLING

Confidential one-on-one professional counselling services are available to persons directly or indirectly concerned about AIDS. Referrals to other professional services are made on request.

SUPPORT GROUPS

For persons who are concerned about their HIV status; who have tested positive for HIV antibodies; for persons with AIDS; for friends, families and partners of persons with AIDS.

ADVOCACY

Assistance will be provided to individuals facing difficulties in receiving services because of their health status.

SERVICES

The AIDS Network works to coordinate the services of supportive public and private agencies in all areas involved by the AIDS crisis.

The services of the AIDS Network of Edmonton Society are provided FREE and on a CONFIDENTIAL basis.



Ross Armstrong Office, 2nd Floor, 10704 - 108 Street
Edmonton, Alberta, T5H 3A3
(403) 424-4767

AIDS NETWORK OF EDMONTON SOCIETY

APPLICATION FOR MEMBERSHIP

NAME: _____

ADDRESS: _____

CITY: _____ POSTAL CODE: _____ PHONE: _____

A \$25.00 membership contributes to the support of persons with AIDS, entitles you to receive a monthly newsletter, and the right to vote at the AIDS Network annual general meeting.

SIGNATURE: _____ DATE: _____
Please notify the AIDS Network if your address changes.

Please inquire about the reduced membership rates for students or the unemployed.



The AIDS Network of Edmonton Society is a member of the
CANADIAN AIDS SOCIETY/LASOCIÉTÉ CANADIENNE DU SIDA